

Frequently Asked Questions Regarding Immunization Registries

(Reviewed 12/12/2003

Revised 12/12/2003)

What are immunization registries?

Immunization registries are confidential, computerized information systems that collect vaccination histories and help ensure correct and timely immunizations, especially for children. Registries are an important tool to increase and sustain high vaccination coverage by consolidating vaccination records of children from multiple providers, generating reminder and recall vaccination notices for each child, and providing official vaccination forms and vaccination coverage assessments. *Healthy People 2010* established a goal of enrolling 95% of children from birth through age five in a fully functioning immunization registry.

Why do we need immunization registries?

The U.S. now enjoys the highest immunization rates and lowest disease levels ever, but the growing complexity of the childhood vaccination schedule makes it difficult to sustain those levels consistently. Approximately 20% of children move by age two. These children often change providers, resulting in incomplete immunization records scattered across healthcare providers. Immunization registries help prevent the “peaks and valleys” of disease outbreaks by managing information about the immunizations that children receive more efficiently.

How might immunization registries work?

Ideally, after obtaining parental consent, a child is enrolled in an immunization registry at birth, possibly through linkage with an electronic birth certificate or at first contact with the health care system. Demographic and immunization data are recorded at enrollment, and electronically transferred to populate the central registry database.

At each immunization encounter, the child’s history is located in the registry’s database with the help of a patient identification algorithm, and downloaded into the provider’s computerized information system. The provider can have confidence that the record is complete and accurate, as the registry will have assembled all immunizations the child has received, regardless of when and where they were administered.

A computerized algorithm using the latest immunization recommendations will assist the provider in deciding whether the child needs be immunized. And when the child is due for an immunization, or has missed an immunization, a reminder/recall notice can be automatically generated by office staff and sent to his or her household.

Staff can keep track of their own immunization efforts by automatically generating ongoing coverage assessments of the practice, and identifying missed opportunities for immunization. And August will become a month not to dread, but to look forward to. Waiting rooms won’t be crowded with parents needing official immunization documentation for school entry – the registry will save time and resources by quickly generating these required documents.

What are some of the benefits of immunization registries?

Immunization registries can be extremely helpful, if not essential, to maintaining the current high immunization coverage. The following is a list of the benefits of registries to parents, providers, communities, and public health officials:

For parents, immunization registries:

- consolidate in one site all immunizations a child has received;
- provide an accurate, official copy of a child's immunization history for personal, day care, school, or camp entry requirements;
- help ensure that a child's immunizations are up to date;
- provide reminders when an immunization is due;
- provide recalls when an immunization has been missed;
- help ensure timely immunization for children whose families move or switch health-care providers; and
- prevent unnecessary (duplicative) immunization.

For providers, immunization registries:

- consolidate immunizations from all providers into one record;
- provide a reliable immunization history for any child, whether a new or continuing patient;
- provide definitive information on immunizations due or overdue;
- provide current recommendations and information on new vaccines; and
- produce reminders and recalls for immunizations due or overdue.

For communities and public health officials, immunization registries:

- help control vaccine preventable diseases;
- help identify high-risk and under-immunized populations;
- help prevent disease outbreaks; and
- provide information on community and state coverage rates.

What is the status of registry development in the U.S.?

Our latest survey data show that in 2002 all 50 states and D.C. were developing or operating registries. On the basis of 2002 U.S. Census denominator estimates, approximately 43% of U.S. children <6 years of age had two or more vaccinations recorded in an immunization registry.

How do immunization registries improve public health?

As an increasing percentage of children are participating in immunization registries, registries are increasing their usefulness to public health programs nationwide. The following are examples of how registries have been used to support public health decision making and to improve public health:

- During the 2001-2002 school year, immunization program staff and school nurses used the Washington, D.C. registry to ensure that local schools were in

compliance with school entry vaccination requirements. Daily, weekly, and monthly reports were generated to track compliance, monitor vaccine inventory needs, and identify pockets of low vaccination within D.C. for further outreach efforts. The registry was used to identify approximately 20,000 children who were not vaccinated properly according to school vaccination requirements.

- In a Utah pilot project, a Web-based application (WebKIDS) was used to link the state registry to a managed care organization's computerized record system. WebKIDS proved to be a timesaving and efficient way to document immunizations for the managed care organization. Health Employer Data Information Set (HEDIS[®]) measurement for its commercial members increased from 65% to 76% and for its Medicaid members from 66% to 77% in a one-year time frame, the most dramatic one year increase to date. The new WebKIDS process resulted in dramatic decreases in time required for immunization administration and documentation; the immunization clinic now only spends an average of 8 minutes and 4 seconds per patient immunized, a decrease of over 3 minutes. Even greater time savings were seen in the creation of other standard immunization reports.
- KITS, the regional Southern California Kaiser Permanente immunization registry, covers almost 3 million members who obtain care at 12 medical centers, and 60+ medical office buildings from 3,000 providers. KITS is considered to have increased the immunization rate for 3 year olds from 63% to 93% for individual immunization, and to 85% on over-all immunizations over a two year period.
- All 12 provider facilities in Wisconsin's Marathon County use the Regional Early Childhood Immunization Network (RECIN) to track immunization data. RECIN allows providers to customize interventions depending on their patient population. For example, a four-tier intervention might consist of a letter, a phone call, a certified letter and a home visit. Initial coverage in Marathon County was 76% in mid-2001. Using tiered intervention, coverage rates improved to 87% in twelve months.
- In Utah, routine inspections of storage refrigerators by Department of Health staff indicated that vaccine in one pediatric clinic had been improperly stored. The statewide registry produced reports identifying patients who received shots at that clinic without having to go through patient medical charts. Fifteen hundred patients were identified for recall and re-vaccination.
- San Antonio used their registry data to evaluate the uptake of the heptavalent pneumococcal conjugate vaccine (PCV7). The analysis suggested that PCV7 implementation was rapid, but that there was significant delay in getting the vaccine to the Vaccines for Children Program (VFC) population. First doses administered to children likely to meet VFC eligibility criteria increased 4-fold once PCV7 was reimbursed by the VFC program.

- One New York City clinic with immunization coverage of 55% received Department of Health feedback based on chart review, and was encouraged to use the City's registry to look up immunization records. Ten weeks following feedback, coverage increased from 55% to 91% for the original cohort of measured children. The clinic successfully recalled under-immunized children, and used the registry to document vaccines administered too soon or at another practice. The registry also validated the clinic's assumptions that some children had moved or transferred elsewhere.
- Oregon used their registry data to track immunization rates for Medicaid children covered by managed care plans. Registry data showed that young children covered through Oregon's Medicaid program had twice the incidence rate of late starts compared to rates for the overall population. These data were powerful evidence to policymakers, Medicaid medical directors, and health plans that late starts for newborns had a negative impact on Oregon's immunization rates. Oregon's Immunization Policy Advisory Team recommended that Medicaid late starts receive priority policy intervention.
- Because only 62% of two year olds in Hennepin County, Minnesota were completely immunized, a registry and outreach program were developed. Based on registry data, 23 zip codes with the lowest immunization rates were targeted for outreach. Registry data were accessed monthly and babies were placed into two categories distinguished by up-to-date status. Babies who fell behind on immunizations were further targeted and received case management, including interpreters when needed, so that resources were directed to those most in need. At 24 months of age, children who participated in the outreach program averaged 94% immunization rates – 21% higher than Hennepin County's average.
- Oregon registry data were used to assess the impact on hepatitis B (HepB) vaccine administration of the Joint Statement of the American Academy of Pediatrics and the United States Public Health Service about using thimerosal as a vaccine preservative. Their joint statement recommended reducing infant exposure to thimerosal; specific recommendations were made to postpone the first HepB vaccine dose until 2-6 months of age for infants born to hepatitis B surface antigen-negative mothers. Oregon's registry data (which includes 88% of the state's population of children < 6 years) indicated the average proportion of children participating in the registry per week who were administered HepB vaccine ≤ 5 days after birth decreased 93% during the 6 weeks after the report's release. On the basis of these data, Oregon officials contacted health plans, health-care providers, and local health departments to ensure that the report's recommendations were followed (i.e., that the first dose of HepB be delayed only for infants born to hepatitis B surface antigen-negative mothers and that providers return to previous infant HepB vaccination practices after a thimerosal-free alternative became available). Continued monitoring of registry data indicated that, despite the availability of thimerosal-free vaccine in August 1999, by the end of 2000, administration rates had reached only 88% of pre-report levels for HepB

vaccination. These data assisted education efforts for providers who had not yet reinstated HepB vaccine recommendations.

- Contra Costa County, California developed the Contra Costa Automated Immunization Registry (CCAIR) in 1995. CCAIR's implementation in public health clinics was associated with increased immunization rates from 55% in 1998 to 84% in 2000, and decreased missed immunization opportunity rates from 7% in 1998 to 3.5% in 2000. By using the CCAIR by WIC staff to assess up-to-date status and implementing a voucher incentive program, the up-to-date rate of children increased from 55% to 69% in the first six months of WIC implementation. CCAIR also was used to identify children who received immunizations at public health mobile clinics, but who indicated no medical insurance and no primary care provider. In four months, clinic outreach staff assisted 17 families to enroll their children in CHIP, and referred 173 families to California's EPSDT for well child exams.
- Immunization registries can direct users to information on proper vaccine storage and handling procedures. They can also support the management of the VFC program. Sixty seven percent of registries operating in the 50 states and D.C. reported using their registries to identify children eligible for the VFC program.

What is CDC doing to reach the HP2010 registry objective?

Provider participation is critical to reaching the Healthy People 2010 objective of increasing to 95% the percentage of children participating in immunization registries. Registries will only be useful if they include immunization histories on a large percentage of the target population. Consequently, they must have active participation from all public and private immunization providers. 2002 data on immunization registries in the 50 States indicated that approximately three-quarters of public provider sites compared with less than one-third of private provider sites were enrolled, a disparity due in part to the initial targeting of registries to the public sector.

The biggest registry challenge may be creating provider demand for registries. Focus groups have indicated that one barrier to participation is concern about the adverse impact that a single-focus information system could have on office practices, by requiring multiple record systems and duplicate data entry. As a result, CDC has been working with billing and practice management software vendors to add value to their products, by creating immunization registry interfaces.

Another stumbling block for provider participation is the current poor quality of registry data. To improve data quality CDC has developed a set of test cases that allow for the measurement of the sensitivity and specificity of de-duplication algorithms currently used by registry developers to uniquely identify registry participants. And CDC is in the process of using the National Immunization Survey, a nationwide, ongoing immunization coverage survey, to evaluate how registry data's accuracy and completeness compares to this Survey's "gold standard" data.

A large part of CDC's current registry activities involves promoting the use of registry data. Currently, eight "sentinel site" registries, known to include a large proportion of their population and to have high quality registry data, have been identified. These sites can demonstrate that registries with quality data can provide valid and reliable estimates of vaccine coverage. By demonstrating the success of registry data use, we can illustrate to providers that registries are authoritative sources of immunization histories.

CDC is also working with an accredited standards development organization, Health Level Seven (HL7), to develop standard protocols for exchanging immunization data between registries. Part of this effort involved the development of a communications tool that registries can use or give to providers to implement standard record exchange. CDC is working with the Indian Health Service to exchange data with immunization registries using HL7, and is working with software vendors to encourage them to build registry interfaces for physicians' offices that use their software for patient management or billing.

How do registries protect privacy and confidentiality?

Protecting privacy and confidentiality is critical for the successful development of an immunization registry. Several state laws that authorize registries or the sharing of immunization information specifically address this issue. CDC has worked with the National Vaccine Advisory Committee, partner organizations, and representatives from state and local health departments to develop minimum specifications (available at <http://www.cdc.gov/nip/registry/priv-confid-sec-legisl.htm#3>) to protect the privacy of registry users and the confidentiality of the information contained in the registry. CDC is also monitoring the potential impact of the Health Insurance Portability Act of 1996 (HIPAA) privacy rule on the development and operation of immunization registries, and working to address issues related to public health and the implementation of the rule.

How much money will immunization registries save?

Estimated annual fiscal savings of \$270.7 million associated with registries include: avoiding manual record pulls for school /day care entry (\$58 million), change in immunization provider (\$16.2 million), and HEDIS quality assurance measures (\$2 million); school system review of immunization records (\$168.0); and preventing duplicative immunizations (\$26.5 million). Other unaccounted cost savings include: decreased no-show appointment rates through the use of reminder/recall notices; avoiding manual production of authorized immunization certificates and checking of these certificates by school nurses and administrative staff; and decreased rates and complications associated with vaccine-preventable diseases.